compassion & choices

MAGAZINE
WINTER 2025

FIVE QUESTIONS FOR
Dolores Huerta

At 94, this iconic advocate is living strong

FREEWILL

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Protect what you love by creating your will today.

Estate planning is an important part of end-of-life planning and essential to protect your family and the causes you care about. You can give yourself and your loved ones the comfort, peace and relief you deserve by taking advantage of Compassion & Choices' partnership with FreeWill.

What Is FreeWill?

Compassion & Choices has partnered with FreeWill, an online will-writing service, to ensure that our community has access to estate planning. Nearly 70% of Americans don't have an updated legal will, despite it being an essential task. Everyone needs an estate plan, regardless of your wealth or where you are in life.

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Open your camera and scan this code to start your free will today!

If you have any questions, contact:

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compassion
& choices
Care and Choice at the End of Life

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Winter 2025
Vol. 24 / No. 1

FEATURES

DEPARTMENTS

Compassion & Choices improves care, expands options and empowers everyone to chart their own end-of-life journey. Learn more at **CompassionAndChoices.org**.

The Compassion & Choices family comprises two organizations: Compassion & Choices (the 501(c)(3) arm), whose focus is expanding access, public education and litigation; and Compassion & Choices Action Network (the 501(c)(4)), whose focus is legislative work at the federal and state levels.

From Personal Advocacy to Movement Leadership

It has been an incredible 10 years since the iconic Dolores Huerta first graced the cover of Compassion & Choices' magazine — a milestone that coincides with the beginning of my own journey at Compassion & Choices, after having served as legal director of the ACLU of Oregon. My admiration for Dolores and the inspiration she has provided stretches back even further, to my early days as a student and young attorney, when I was deeply involved in organizing and advocating for the rights of migrant and seasonal farmworkers.

We are absolutely thrilled to honor Dolores Huerta's unparalleled legacy of advocacy and groundbreaking accomplishments in this issue. Over the past decade, the end-of-life movement has made extraordinary strides, and Dolores has been a powerful force, amplifying the voices of those seeking an equitable, compassionate end-of-life experience that reflects their values and priorities. Her tireless dedication continues to light the way forward, and we are profoundly grateful for her enduring impact and leadership.

Advocating for a loved one or friend is central to serving as a surrogate healthcare decision-maker or proxy. In a pair of stories, we explore responsibilities and communication in end-of-life care. *Communicating Effectively with Medical Providers at the End of Life* (page 4) discusses how to advocate with medical providers on behalf of someone else. If you are called upon to act as a surrogate or proxy for someone you love, *Being a Surrogate Healthcare Decision-Maker* (page 8) will help you understand the responsibilities and requirements — and what questions you should ask to be the most effective advocate you can be.

The Medical Aid in Dying Residency Requirement (page 6) explains the residency limitations of some medical aid in dying laws. Vermont and Oregon, which do not have any residency restrictions, are options for terminally ill people who have the resources and support to travel to another state. This article offers factors to consider before making that journey.

Thank you for all you do. Your ongoing support of Compassion & Choices and this movement is creating meaningful change for all people. As one of my heroes, Dolores, reminds us all … ¡Sí se puede! — Yes we can!

With gratitude,

Kevin Díaz, JD, *Interim President and CEO*

compassion & choices
MAGAZINE

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In the Media

Delaware News Journal

Facing imminent death, he wanted to go on his terms. Why governor's inaction prevented that

After being diagnosed with esophageal cancer at 79, Chuck Knothe of Delaware endured chemotherapy, radiation, and major surgery. Unfortunately, his health quickly deteriorated as the cancer metastasized, leaving him in unrelenting pain that hospice care could only partially ease. Chuck was never an advocate for medical aid in dying before his diagnosis, but his suffering brought a new perspective. In his final days, Chuck hoped to see the Ron Silverio/ Heather Block Delaware End-of-Life Options Act pass, so that terminally ill patients like him could choose to peacefully end life on their own terms. Despite momentum, Governor John Carney vetoed the proposed legislation in October, just a few days after Chuck died.

Chicago Tribune

Op-ed gets it wrong about medical aid-in-dying safeguards

Illinois advocate Andrew Howard, MD, fired back in a letter to the editor of the Chicago Tribune criticizing inaccuracies in a recent op-ed that equated suicide to medical aid in dying for terminally ill patients. "They seem to conflate people in the throes of mental health crises who die by suicide and mentally capable, terminally ill adults who want the option of medical aid in dying to peacefully end unbearable suffering at the very end of life," he wrote — highlighting that aid-in-dying laws in the U.S., including the proposed Illinois End-of-Life Options Act (SB 3499), have strict safeguards to protect patients, allowing only mentally capable, terminally ill adults with six months or less to live to self-administer medication.

KFF Health News

Traveling To Die: The Latest Form of Medical Tourism

In August, KFF Health News wrote a story about Francine Milano's decision to travel from Pennsylvania to Vermont after receiving a terminal diagnosis of ovarian cancer. "I really wanted to take control over how I left this world. I decided that this was an option for me," said Milano, 61, a Lancaster resident. Since Vermont lifted its residency requirement in May 2023, at least 26 people have traveled there to die peacefully. Milano is grateful she has the power to do so now, while she's still healthy enough to travel and enjoy life. "I just wish more people had the option."

Hospice News

Asian-American Communities Face 'Digital Divide' in Health Equity, Hospice Care

Hospice News interviewed Compassion & Choices Asian American, Native Hawaiian, and Pacific Islander (AANHPI) Leadership Council members Victoria Tsze and Dr. Mitsuo Tomita about the disparities Asian American communities face in accessing telehealth. "A reliance on virtual healthcare can exacerbate inequities for Asian Americans if attention is not paid to ensuring language access, improving cultural competence amongst providers, and supporting patients and caregivers in gaining greater digital literacy," Tsze said. "It risks limiting people's access to the health care and support they need at the end of their lives. When people lack access to care, they are less likely to have adequate pain management during the dying process and are more likely to have aggressive and invasive treatments at the end of life."

Communicating Effectively with Medical Providers at the End of Life

Avoiding a clash between clinical values and patient priorities.

Completing your advance care plan and discussing it with your chosen healthcare proxy and medical providers are the best ways to access the care you want. An unexpected crisis can trigger the need for end-of-life care at any moment. Even when someone has a long-term illness or chronic disease, the end can feel sudden. In these moments, reactions and actions will determine whether your values and priorities are understood and respected. How can you be ready to communicate with healthcare providers for whatever comes next?

Advance care planning refers to the process of thinking about, discussing, and writing down your wishes and priorities for future medical care. Your advance directive (also called a living will) should focus on what YOU want — and WHO you want to make decisions on your behalf. Other terms for this role include surrogate decision-maker, proxy, durable power of attorney for healthcare, or medical power of attorney.

Ideally, advance directives are shared with care providers and loved ones long before an emergency arises, to ensure others are aware of your wishes well in advance. Take the time now to discuss them with your chosen surrogate so they know how to make decisions on your behalf. It can be terrifying to witness a medical crisis and watch as a dying friend or loved one struggles to breathe, endures pain, or experiences extreme discomfort. Even when someone is already receiving hospice care, a loved one may need to call emergency services for assistance.

Remember, emergency department (ED) teams are trained to save lives. This means their default is to provide full and aggressive treatment — unless they have specific and legally binding directions that say otherwise. The concept of providing palliative care in EDs has long been explored, and Compassion & Choices National Emergency and Palliative Medicine

Initiative (NEPMI) is working to transform care by highlighting the benefits and promoting the integration of palliative care in emergency settings. However, this option is not yet available for all, so it is a good idea to learn how your local emergency department approaches patients who are nearing the end of life.

Walking into an ED with documents in hand is helpful, but does not guarantee the medical team will follow the patient's wishes. Consider this possibility when choosing your advocate or proxy. If you can't speak for yourself, will your proxy stand firm and insist that medical providers observe your stated wishes, or will they defer to doctors and hospital personnel?

At these moments, hospital conversations focus on goals of care (GOC), which means determining immediate next steps. First and foremost, make sure your medical team has an up-to-date copy of your advance directive, POLST (Physician Orders for Life-Sustaining Treatment, if you have one) and contact information for your chosen surrogate decision-maker. Then, depending on whether or not you are able to speak for yourself, you or your surrogate can ask questions to confirm the medical team understands your wishes. Try using the questions below to evaluate decisions and get clarity.

According to Jena Johnson, senior end-of-life consultant at Compassion & Choices, "I speak to some families who complete advance care planning. Then there is a crisis, and the family calls 911. In the heat of the moment, no one thinks to bring along those documents. In one instance, a man was dying of congestive heart failure. In the ED, the family wanted only comfort care. This conversation with the physician became very heated. The physician was adamant the man received invasive treatment. But the daughter stood her ground. The man was transferred to hospice the next day and died comfortably 18 hours later without those unwanted treatments."

Often, medical professionals feel it is their job to provide hope to patients and their loved ones, believing that everyone wants to live as long as possible. But many patients hope to not suffer … to have some control … and for a death that aligns with their values and priorities. You and your loved ones can achieve this through thorough planning, open communication with your clinical team, becoming fully informed about tests/treatments and standing your ground in your decision making.

Vital Questions to Ask Before Consenting to a Treatment

From Finish Strong, Putting Your Priorities First at Life's End (2nd Edition), Barbara Coombs Lee

- What is the goal of this treatment (i.e., the expected outcome or response)?
- What proportion of patients who receive this treatment achieve that goal? (In other words, how often does it work for people in similar circumstances?)
- If the goal is to prolong life, what is the expected increase in life expectancy, in months or years?
- What are the risks or side effects? How often do these occur?
- How will this treatment affect my quality of life? What is the expected frequency, duration, and recovery time for each treatment?
- Is there a chance this treatment will make my condition worse?
- What are other treatment options? Are there additional options beyond those you have mentioned?
- What will likely happen if I decline this or any treatment, and when is that result likely to occur?

The Medical Aid in Dying Residency Requirement

Relocating to another state to access medical aid in dying.

Compassion & Choices advocates for end-of-life options, including medical aid in dying, for all — regardless of a person’s ZIP code. Today, 10 states (California, Colorado, Hawai‘i, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington State) plus Washington, D.C., authorize medical aid in dying for a person 18 years old or older, who is mentally capable of making medical decisions, has a prognosis of six months or less to live, and is able to self-ingest the prescribed medication. Outside of these jurisdictions, how can people who want medical aid in dying access the option?

Apart from Vermont and Oregon, which do not have residency restrictions — a direct result of Compassion & Choices’ lawsuits — every other state where medical aid in dying has been authorized via the legislative process has statutory language that limits the use of the practice to in-state residents. Terminally ill residents of other states are prohibited from accessing the medication, healthcare, and related services unless they have legally established residency.

Relocating to access medical aid in dying can be extremely burdensome for someone with a terminal illness, due to a limited timeframe, restricted mobility, the need to find a supportive healthcare team, lack of financial resources, and possibly reduced support from family and friends. According to the Oregon Health Authority 2023 Data Summary, only 23 people from out-of-state died using medical assistance in 2023 in Oregon, representing just over 6% of the total who used medical aid-in-dying that year.

Ashley Fry, DNP, director of clinical advocacy at Compassion & Choices, shares, “Individuals who meet the criteria for medical aid in dying and have a very limited life expectancy may be experiencing advanced symptoms such as weakness, fatigue, pain, or shortness of breath. They may require the use of oxygen for disease management and/or comfort.

Care of these individuals requires diligent symptom management to ensure they can travel safely and comfortably to a jurisdiction where medical aid in dying is authorized."

Fry says hospice care in one's home state is beneficial for providing expert symptom management near the end of life. Hospice offers specialized care that focuses on compassion, quality of life, and comfort during a person's final months.

Terminally ill people who can relocate have more options, but they may also face hurdles. They will need to find a practicing doctor in-state who is willing to prescribe the medication and a local pharmacy to fill the prescription. Anyone interested should explicitly identify a local doctor who will support a request for medical aid in dying and confirm eligibility under that state's law before beginning the process of transferring care.

In 2023, Compassion & Choices filed a federal lawsuit on behalf of two New Jersey doctors and cancer patients in Delaware and Pennsylvania asserting the residency mandate in New Jersey's medical aid-in-dying law violates the U.S. Constitution's guarantee of equal treatment. Currently, New Jersey allows only residents to access aid in dying, prohibiting access for non-residents.

Plaintiff Judy Govatos, who lives in neighboring Delaware, said, "I'd like not to die in terrible pain and terrible fear. Having the option to use aid-in-dying medication in my own state, when I decide to, would be an act of mercy and kindness. For now, it would be an incredible gift to be able to go to New Jersey."

To determine if relocating is the right choice for you or your loved one, start by answering the following questions. These apply in all jurisdictions except Oregon and Vermont, which have removed the residency restrictions and now allow medical practitioners to help non-residents obtain medical aid-in-dying services.

Factors to Consider Before Relocating to Access Medical Aid in Dying

○ What is the target state's requirement for establishing residency?

○ How will you find and establish care with a new healthcare team?

○ Have you identified a provider who is licensed, practicing, and willing to prescribe the medication?

○ How is your mobility? Symptom management?

○ Do you have family and friends in the state?

○ Will any family and friends be able to relocate with you or support you from afar?

○ Where will you live?

○ Can you transfer current medications to another state?

○ Do you have the financial resources to support yourself and meet your healthcare needs in another state?

○ How do you feel about potentially being away from your home and social support network at the end of life?

For additional information, visit **CompassionAndChoices.org/legal-advocacy/residency-restrictions**

Being a Surrogate Healthcare Decision-Maker

Serving as a surrogate healthcare decision-maker, agent, or proxy can be daunting, especially if you are unsure of what to expect. This will help you prepare.

What can you do as a healthcare surrogate or proxy?

You are the one designated and trusted by the patient to make healthcare decisions for them if/when they become unable to speak for themselves. Typically, you can speak with a patient's healthcare team, make decisions about starting/stopping care, sign healthcare-related consent documents, access medical records, and take other healthcare-related actions on the patient's behalf. Since surrogates are often required to make decisions in a crisis, make sure you are 100% comfortable representing the wishes of the person you represent even under extreme pressure.

Surrogates do not manage finances or personal affairs. Nor can you transfer authority to someone else. If you are unable, unwilling, or unavailable, decision-making authority will transfer to an alternate designated in advance by the patient.

Your authority is determined by the advance directive of the person you represent. Many advance directive forms allow people to choose when your authority becomes effective, whether immediately or after a physician has determined that the patient has lost decision-making ability. Similarly, the advance directive will indicate what authority you maintain after the patient's death, in compliance with state laws.

How can I be an effective surrogate healthcare decision-maker?

- Be sure you have all the information needed to make informed decisions. This includes staying current about the patient's condition, treatments, and medications — and most importantly, understanding their wishes for future care.
- Understand and use the Vital Questions About Treatments on page 5 in conversations with the clinical team to get information and evaluate options.
- Always keep a copy of the patient's current advance directive and signed POLST (Physician Orders for Life-Sustaining Treatment) on hand and be prepared to provide copies as needed.
- If the person you represent does not want life-extending measures to be taken, make sure they have a valid do not resuscitate (DNR) order in their POLST, and that it is easily located in the event 911 is called.
- Be sure others are aware that you are the chosen surrogate decision-maker. Make sure you have contact information for the patient's loved ones, medical providers, and other important people — and that they have yours.
- If the patient still has decision-making capacity, find ways to be a source of support, such as participating in care meetings, taking notes, and coordinating appointments.

What do I do if the person has been admitted to the hospital?

- Make sure the care team is aware of the patient's wishes.
- Make sure the hospital has the most current copy of the patient's advance directive and POLST; do not assume it is already on file.
- Provide your contact information and make yourself available. If the patient is unable to make

decisions or verbalize their wants and needs, you should be at their bedside if at all possible.

- Don't be afraid to speak up, ask questions, and advocate for your person. If a situation requires more discussion, ask for a family or care team meeting to gain clarity on next steps.
- Determine who is the best person to keep you informed of the patient's condition. In a hospital, this is more likely to be the care manager, bedside nurse, discharge planner, or another member of the team other than the doctor.
- If you need help communicating, making decisions, or getting your questions answered, ask for help from the hospital's patient representative, social worker, chaplain, or other support person.
- Remember, in this role, you are an advocate. Don't be afraid to speak up, ask questions, and make yourself heard. Be assertive as necessary.

Circumstances in which following a patient's wishes may not be possible.

Providing care for a person who requires 24-hour-a-day assistance may require a shift in plans. Work with loved ones and the care team to make the best decisions possible with the information available to you. Here are some possible scenarios:

- The person wants to remain at home but would require around-the-clock care, which may not be physically or financially feasible.
- The person doesn't want "strangers" coming into their home to provide care, but you aren't able to provide around-the-clock care yourself.
- The person hopes to die at home, but is in such a fragile state that leaving the hospital is not possible.
- The person prefers to remain in the hospital for their final days, but that is not possible based on space, coverage, or health system discharge policies.
- The person's advance directive indicates their desire for aggressive, life-sustaining measures, but the risks outweigh the benefits (i.e., they are not a candidate for surgery, or IV nutrition/fluids would cause more harm than good).

Use these prompts to foster discussions between you and the person you represent while they are still able:

- Nutrition and hydration: If you can't eat or drink for yourself, do you want to be fed artificially or by hand? If not, are you comfortable receiving medication through a patch, suppository, or sublingually?
- Infections: During hospitalization or confinement to bed, you may experience pressure sores, urinary tract infections, or pneumonia. Do you wish to receive treatment for these conditions?
- Supported breathing: If you are unable to breathe on your own, do you want to be intubated or receive breathing assistance?
- Comfort care only: Do you want to exclude curative or aggressive treatments and receive only those that keep you comfortable during your dying process?

For more information on end-of-life planning and free tools and resources, visit **CandC.org/eolc/finish-strong-tools**

Sources: Guide to Being a Health Care Proxy, The Conversation Project (2021); Choosing a Healthcare Agent, CaringInfo (2024); What is a Health Care Agent, WebMD (2022) national programs update

C&C Participates in CBC Foundation’s Annual Legislative Conference (CBC ALC)

Compassion & Choices took part in 2024’s Congressional Black Caucus Foundation (CBCF) Annual Legislative Conference (ALC) in Washington, D.C. The ALC is a policy conference dedicated to addressing key issues affecting African Americans and the global Black community. In its 53th year, this event provided space for thought leaders, lawmakers, influencers, and engaged citizens to come together and tackle pressing concerns, build partnerships, and advocate for political, economic, and social progress.

Nine members of the Compassion & Choices African American Leadership Council (AALC) engaged with legislators, healthcare leaders, and other decision-makers to discuss the need for heightened awareness around end-of-life care. The team attended conference sessions, issue-based forums, and networking events aimed at advancing health equity. Being present in this way allows Compassion & Choices to expand its reach and strengthen relationships with key leaders and policymakers.

AALC member Bobbie Alexander said, “I am deeply honored to be a member of this council and to have the privilege of attending the 2023 and 2024 CBC Annual Legislative Conferences. It was truly invaluable to be in community with AALC members who advocate for end-of-life planning, while also sharing space with such an inspiring representation of Black excellence.”

Compassion & Choices African American Leadership Council members and staff attend Congressional Black Caucus events in Washington, D.C.

While gathered in the nation’s capital, several council members participated in Starks Films’ Black Barbers Doc podcast series. They discussed how valuable the conference was for connecting with communities as well as the importance of making informed end-of-life care decisions, having conversations about death and dying, advance care planning, and understanding the impact of healthcare inequities at the end of life.

By maintaining such a strong presence at the conference and attending multiple events, AALC members gained insights that will guide future empowerment and engagement efforts. The AALC looks forward to using these insights for strategic planning that will strengthen our advocacy for equitable end-of-life opportunities.

Supporting Federal Legislation for End-of-Life Options

Compassion & Choices is supporting several federal bills that would improve end-of-life care and autonomy for everyone. By developing resources, providing educational materials, and fostering relationships with members of Congress, we can effectively advocate for legislation that will support end-of-life choices and empower individuals to make personal decisions about their final days.

One such bill that Compassion & Choices supports is HR 8137, also known as the Patient Access to End-of-Life Care Act. Passage would exempt states and jurisdictions that have authorized medical aid in dying (currently and in the future) from the provisions of the Assisted Suicide Funding Restriction Act of 1997 (ASFRA). Currently, ASFRA prohibits the use of federal funds to pay for medical aid in dying for mentally capable, terminally ill adults. HR 8137 would pave the way for patients in authorized states to receive medical aid in dying services at federally funded facilities. In addition, the bill would allow Medicare, Medicaid, and military and federal employee health care plans in authorized states to cover medical aid in dying, including clinician visits to determine eligibility and the medication itself.

Collaborating to Advance End-of-Life Care and Planning with Latino Communities

Compassion & Choices partners with the Latinx Task Force, a national initiative, to address the health disparities and inequities experienced by Latinx communities. The Latinx Task Force shares Compassion & Choices' bilingual resources on its website and through its newsletter to help people access information and support to plan for care during a medical emergency or at the end of life.

During Hispanic Heritage Month last fall, Compassion & Choices co-hosted in-person and virtual events with Latinx Task Force and Face to Face, a Latino-focused organization serving families impacted by dementia. The events, which were provided in Spanish, addressed caregiving, dementia, and end-of-life planning for Latinos.

Compassion & Choices, Latinx Task Force and Face to Face collaborate on a dynamic in-person and virtual event in Corpus Christi, Texas.

In January, we collaborated on a webinar addressing health equity and disparities at the end of life. This spring, we look forward to co-hosting another virtual event for National Healthcare Decisions Day (April 16) and an in-person workshop in May.

Strategic partnerships with groups like the Latinx Task Force enable Compassion & Choices to help more communities make informed decisions about their healthcare.

Connecting with AANHPI Advocates, Clinicians, and Communities

Compassion & Choices reaches more people with vital end-of-life information and healthcare resources by participating in and sponsoring events with Asian American, Native Hawaiian, and Pacific Islander (AANHPI) communities.

In November, Compassion & Choices connected with Filipino-American clinicians as an event sponsor of the Philippine Nurses Association of America's (PNAA) South Central Regional Conference in Houston, Texas. The PNAA provides its 5,000+ national members with mentorship, leadership development opportunities, and educational programming.

Taiko drumming at the Big Island Art and Science Summit in Hilo, Hawaiʻi.

Last September, Compassion & Choices attended and sponsored the 2024 AANHPI Unity Summit in Washington, D.C. This annual event, hosted by the Asian American Unity Coalition, aims to foster civic engagement, strengthen advocacy skills, and offer AANHPI leaders a platform to voice concerns. In 2024, the summit addressed pressing issues that impact AANHPI communities, such as racial discrimination and immigration, and gave attendees the opportunity to engage in advocacy with their elected officials.

Compassion & Choices also continues to reach and engage with communities through the arts. In October, we participated in and sponsored the Big Island Art and Science Summit in Kailua-Kona, Hawaiʻi, an event designed to stimulate a thriving arts economy and foster artistic exchange across the Pacific Islands. With more than 1,000 attendees, the summit featured music, dance, Pacific and Native Hawaiian cultural presentations, art installations, an art market with local vendors, breakout discussions, hands-on workshops, and other activities.

Compassion & Choices Chief Engagement Officer Brandi Alexander delivered an opening keynote address, following introductions by Hawaiʻi state Senator Tim Richards and Representative Nicole Lowen and Hawaii County Mayor Mitch Roth. Compassion & Choices had a table display to share free materials related to healthcare decision-making and end-of-life care. It was a beautiful day of education, creativity, and cultural celebration that served to deepen our ties with community members in Hawaiʻi.

Bishop Kevin E. Taylor Serves Communities Across The Nation

Bishop Kevin E. Taylor, a faith leader in Newark, New Jersey, provides a crucial perspective to Compassion & Choices Faith Leaders for Compassion and LGBTQ+ Leadership Council. An advocate for improving end-of-life care for all communities, last October Bishop Taylor was elevated to the role of a bishop during a ceremony in Riverside, California. Compassion & Choices was there to celebrate and provide resources to congregants. Over 200 people attended his convocation, which honored his work and commitment to fostering conversations, information, and resources to support the LGBTQ+ community's end-of-life needs and concerns. We also hosted an end-of-life planning and care conversation for approximately 50 participants from his congregation. Bishop Taylor is planning a series of conversations in 2025 entitled *New Year of No Fear: Conversations About Death, Dying, Choices, and Getting Your House in Order!*

Top: Bishop Kevin E. Taylor in celebration with community members at a ceremony in Riverside, California.

LGBTQ+ Engagement Reaches New Heights

Compassion & Choices continues to work with the LGBTQ+ community by offering tailored resources and being present at events, virtually and in person. Last October, Compassion & Choices participated in a month-long event staged by the Collective for Radical Death Studies that culminated in a virtual event about end-of-life planning in the LGBTQ+ community. We also added the LGBTQ+ Advance Care Planning toolkit, created in partnership with SAGE, to the curriculum at University of Florida College of Medicine. Compassion & Choices staff and supporters continued to participate in Pride events across the country from Seattle to Georgia throughout the fall, including Global Black Pride in Atlanta, Georgia. We also sponsored and participated in the Gay & Lesbian Medical Association's annual conference in Charleston, South Carolina, providing a talk on advance care planning to clinicians.

state spotlight

Illinois Lawmakers Prepare to Consider Medical Aid in Dying Bill

Advocates hope to pass a bill that expands options for terminally ill Illinoisans.

The Illinois End-of-Life Options Coalition and advocates across the state are gearing up in full force to advocate for the End-of-Life Options Act.

"We are grateful that lawmakers are listening to the majority of Illinoisans who support this compassionate bill that would give terminally ill adults the option to die peacefully without unnecessary suffering," said Callie Riley, regional advocacy director for Compassion & Choices. "Dying Illinoisans do not have time to wait for another legislative session. We urge legislators to pass the End-of-Life Options Act as soon as possible, so dying adults in Illinois are not forced to suffer or move to another state to die peacefully."

Recent polling shows that 7 out of 10 likely voters in Illinois (71%) want the legislature to pass medical aid-in-dying legislation. More than 6 out of 10 Illinois physicians (62%) would personally want the option of medical aid in dying if they become terminally ill, while only 1 out of 5 (20%) would not want it.

The bill is especially important to Deb Robertson, a retired social worker with an extremely rare and aggressive cancer. "I've done everything I can to cure my cancer, including enduring multiple cycles of chemotherapy. But the bottom line is, I'm already dying," she said. Medical aid in dying "would allow me to die peacefully. It would allow my wife and family to say goodbye, and to know that it's okay to let go."

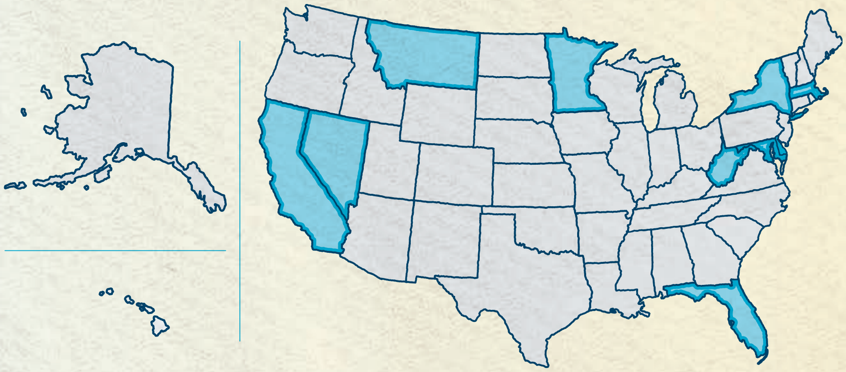
Top: Deb Roberson and her dog Nellie, Bottom: Suzy and Andrew Flack

Suzy Flack understands firsthand the impact of authorizing medical aid-in-dying laws. Her only son, Drew, a special education teacher and avid hockey player, spent the last months of his life advocating for medical aid in dying in Illinois, his home state. Drew had moved from Illinois to California before he became ill, so he was able to use California's End of Life Option Act. He died on Nov. 16, 2022, at just 34 years old. Before he died, Drew recorded a video for Compassion & Choices and discussed his support for medical aid in dying on his blog and podcast.

"Andrew died peacefully because of the option of medical aid in dying in California, where he lived," Suzy said. "I am comforted by this, but I wish my son could have had that option here in Illinois."

M.A.I.D. in the USA

Highlights of state efforts to expand end-of-life options for all.



CALIFORNIA

The California team continued to solidify support among diverse communities to improve access to the End of Life Option Act and make the law permanent before it expires in 2031. We participated in more than 30 events, including four Spanish-speaking events and San Diego Pride, and hosted a webinar on faith engagement. The success of our outreach was evident when a new report by the California Department of Health revealed that those choosing medical aid in dying are the most diverse by race and/or ethnicity since the law took effect. We will continue to educate new legislators about the law in 2025.

DELAWARE

In September, after months of inaction, outgoing Governor John Carney vetoed HB140, putting his personal beliefs ahead of the 72% of Delaware voters who support the option of medical aid in dying. Despite this blow, Compassion & Choices Action Network is optimistic about the next legislative session. The Delaware team, alongside new bill sponsor Rep. Eric Morrison and Senate Majority Leader Bryan Townsend, is working hard to regain the momentum we achieved when HB140 passed the General Assembly in 2024. Incoming Delaware Governor Matt Meyer has promised to sign the law if it comes to his desk.

FLORIDA

Our Florida team had a productive fall, engaging with communities across the state. At the 15th annual Active Aging Expo, we shared valuable resources in English and Spanish about end-of-life options, including medical aid in dying, with the LGBTQ+ aging community. The team also joined the 2024 Eudēmonia Summit, a transformational wellness conference, where we connected with a diverse group of new supporters. Additionally, we produced a heartfelt Day of the Dead video to honor families throughout the state, which was posted on Facebook. The team is excited to collaborate with supporters in spreading Finish Strong resources statewide.

MARYLAND

While the End-of-Life Option Act did not move forward for a vote in 2024, Team Maryland's advocacy remains unwavering. We hosted three community screenings of *Last Flight Home*, filmmaker Ondi Timoner's documentary about her father's final days, and participated in numerous outreach events, including the Heritage Harbor Health Fair, the Unitarian Universalist Legislative Ministry of Maryland's annual Engage UUCA, and the King Farm Fall Festival. We have also been working with a new Senate sponsor, Judiciary Committee Chair Will Smith, and are hopeful of seeing movement under his leadership.

MASSACHUSETTS

Our Massachusetts team is keeping up community engagement in hopes that 2025 is the year that the End of Life Options Act finally becomes law. In September, volunteer Nadia Prescott recorded an interview for the Beverly Council on Aging about end-of-life options for seniors, including medical aid in dying. In 2025, we will focus on expanding legislative support by engaging with newly elected and non-committal legislators and reengaging incumbent bill sponsors to raise the profile of the bill.

MINNESOTA

In October, Minnesota's Campaign & Advocacy Manager Gina Schneider hosted Minnesota's annual benefit, *Renewing the Promise: Compassionate Choices for All*. Gina was joined by Serene Meshel-Dillman, filmmaker and director of *Take Me Out Feet First*, a docuseries about medical aid-in-dying advocates across the nation. Dan and Candy Nelson, parents of late Minnesota storyteller Danna Nelson, are featured in the docuseries. The group graciously participated in an emotional Q&A panel onstage. Gina also honored Representative Mike Freiberg and Dr. Rebecca Thoman for advancing the Minnesota End-of-Life Options Act further than ever last year.

MONTANA

Team Montana is extremely engaged in the community in preparation for the 2025 legislative session, when we anticipate a bill to criminalize medical aid in dying to be introduced. Through summer and fall, Compassion & Choices Action Network sponsored and/or attended Pride events in Missoula, Billings, Butte, and Big Sky; the Madison County Fair; the Montana Healthcare Conference; and the Montana Nurses Association Convention. We also hosted a campaign briefing in September with information about the history and future of end-of-life options in Montana.

NEVADA

After a disappointing veto by Governor Joe Lombardo in 2023, Compassion & Choices Nevada supporters are pushing for a medical aid-in-dying bill during the 2025 legislative session. In the fall, a survey by the Nevada Public Opinion Pulse showed an overwhelming 63% of Nevadans support medical aid in dying as a compassionate end-of-life option. Support crossed party lines, with 80% of Democrats, 46% of Republicans, and 60% of independent voters. Our team continues to build relationships with storytellers, legislators, healthcare providers, community organizations, and others to advance the full range of end-of-life options.

NEW YORK

In November, the New York State Nurses Association (NYSNA) adopted a resolution in support of New York's Medical Aid in Dying Act. Advocate Denise Griffin, a nurse and NYSNA member from the North Country, sponsored the resolution. The group joins more than 50 other statewide and grassroots groups that support the bill.

Compassion & Choices welcomed Brooklyn resident Erin Markman to its Storyteller program in the fall. After receiving a terminal cancer diagnosis, Markman's father died peacefully in California with loved ones at his side after taking aid-in-dying medication. Her experience witnessing a "good death" inspired Markman to advocate for the compassionate option of medical aid in dying for terminally ill New Yorkers. On January 28, she joined Dan Diaz, Rev. Charles McNeill, New York-based supporter Scott Barraco, and Dr. Jeremy Boal, a former healthcare executive living with ALS, for *Freedom + Autonomy at Life's End: A Discussion About Medical Aid in Dying*, a forum organized by C&C and sponsored by the political magazine *City & State*.

WEST VIRGINIA

On November 5, West Virginia voters narrowly approved Amendment 1, which adds a prohibition against medical aid to their state constitution. West Virginia is the first state in the nation to take this regressive action.

"The constitution is no place to regulate health care for terminally ill people," said Charmaine Manansala, Chief Advocacy Officer for Compassion & Choices. "This is just the beginning. We should expect the possibility of ballot initiatives like this in other states. Compassion & Choices will be there to protect patient-directed care and bodily autonomy at the end of life wherever those rights are threatened."

Five Questions for Dolores Huerta

Last interviewed for Compassion & Choices magazine 10 years ago, Dolores Huerta, the iconic civil rights activist, is an inspiring force in the end-of-life options movement. She was the inaugural recipient of Compassion & Choices Dolores Huerta Mission and Vision Award for her commitment to expand and protect options at the end of life. At 94, she remains as active and powerful an advocate as ever for people to finish strong. Even today, Dolores Huerta is living strong.

Since you were interviewed by Compassion & Choices in 2015, there have been many changes in the end-of-life options movement. How do you feel about the progress we have made and the journey ahead?

The movement has come a long way since I joined terminally ill Californians who wanted the option to request medication to die peacefully. I partnered with Compassion & Choices at a time when Latinos were very reluctant to speak about our mortality and how to plan for death.

It is exciting to see Compassion & Choices uplifting the voices of underserved communities who were typically left out. They created leadership councils for Latinos, African Americans, Asian Americans, Native Hawaiians, and Pacific Islanders, LGBTQ+, and other communities. As a member of the Compassion & Choices Latino Leadership Council, I have seen us gain different perspectives and experiences that allow us to understand the challenges facing diverse communities.

It is very rewarding to see Compassion & Choices deliver culturally appropriate materials in Spanish for Latinos to understand without having the confusion of trying to read it in English and translate it themselves. We have made tremendous progress, but we still have barriers that we need to break to ensure that no one is left behind. We must continue working together to eradicate healthcare disparities so all people living in America have equal access to the full range of end-of-life care options.

The reality is that we are all going to die. We need to talk about it more. We must take advantage of our time on this earth to plan for our mortality and help prepare others for it, as well.

Planning and communicating is such a critical part of ensuring end-of-life autonomy. How has the movement influenced your own feelings about end-of-life planning?

Working with Compassion & Choices has certainly opened my perspective on the importance of planning for the inevitable. In fact, the disproportionate deaths and healthcare disparities among Latinos during the pandemic made the issue of advance care planning more urgent than ever before.

We must continue to come together as a society to make a bigger impact. It is critical for doctors and healthcare providers to engage in effective end-of-life conversations with their patients. Our *gente* [people] must have the mentality that planning for the end of life is as important as paying taxes. We must take advantage of our closeness with our *familias* [families] to talk about what we want at the end of our lives. We must continue to talk to our doctors to prepare for an illness or a time when we can no longer speak for ourselves. We have the power and responsibility to create change. We can do it. *Sí se puede* [Yes we can].

You have been a powerful advocate for social and human rights issues for many years. What accomplishments are you most proud of?

I have spent my life fighting for better working conditions and the rights of disadvantaged workers, immigrants, and women. I take immense pride in working with Compassion & Choices in improving care, expanding options, and empowering everyone to chart their end-of-life journey.

This issue is very personal to me. I watched my mother suffer horribly before her death from the cancer that spread all over her body. Although this horrific experience happened over 50 years ago, the painful memory of her suffering still lingers. Working with Compassion & Choices is a way to honor my mother. That is why I joined terminally ill Californians to help pass a law to authorize the expansion of options for the end of life, including medical aid in dying, that took effect in 2016. And, that is why I continue to reach out to legislators across the country to seek their support.

> “Let’s knock on as many doors as it takes to open them, no matter how closed they may be.”

In the last 10 years, I have seen the passage of seven laws that expand end-of-life options and the introduction of dozens of bills nationwide that intend to do the same. I also had the opportunity to help pass a law to improve access to the California End of Life Option Act, so that terminally ill adults and their families can more easily access the law without needless suffering and unnecessary roadblocks. These monumental achievements are testaments of diverse communities coming together and not giving up to support this basic human right. My mother always taught me to fight, serve the poor, and never let others dictate what I believe in. I believe this is what keeps me going at 94.

What advice would you give someone new to advocacy work who aspires to have the kind of influence you have had in creating real change?

I strongly believe in the power of working together to bring change. We must organize and fight for something we truly believe in. We don’t need to have a recognized name to bring change. Average people can make a difference. We must always look for opportunities to help others in need, come

together, and organize as a community. The greatest changes in history were made from people coming together, by fighting for what they believe in without the fear of being shut down.

I encourage you to come forward. Rally, scream as loud as you can. Stand for justice and what to believe in and take action. Let's knock on as many doors as it takes to open them, no matter how closed they may be. As I often say, we have to convince ourselves that we have the power to make a difference. Once we come together as a community, we will empower ourselves and fight injustices. That is the power of organizing and something we can all do together.

Latino support for end-of-life autonomy has increased in the last 10 years. How have you contributed to that?

Latino support for medical aid in dying has increased tremendously since I partnered with Compassion & Choices. Today, more terminally ill Hispanics in California have accessed the End of Life Option Act, accessing medical aid in dying.

A California Department of Health report on the End of Life Option Act released in 2024 showed 79% more Hispanics in California used the state's medical aid-in-dying law in 2023 compared to the less than 3% who used the law in 2022.

It warms my heart to embrace people who come up to me and thank me for helping to open the conversation about planning for the inevitable. They tell me they are fighting for their values and their priorities. They are not allowing anyone to dictate their end-of-life journey. These are the stories that bring change: the stories from mothers, fathers, daughters, sons, sisters, and brothers who knock down the strongest doors to convince others what they believe is best for them. These are the people who help convince legislators what they want at the end of their lives. These are the people who help make a difference on what they want at the end of their lives. I am only here to help amplify their voices.

From top to bottom: with Bill Monning and Compassion & Choices Chief Advocacy Officer Charmaine Manansala; April 2019 press conference Nevada State Capitol; with Susan Talamantes Eggman at August 2015 California hearing; December 2015 press conference in California

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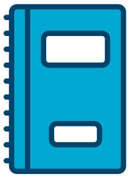

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